Parents' Experiences, Reflections, and Hopes as their Children with Disabilities Transition to Adulthood[1]

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The purpose of the study was to explore the perspectives of five mothers of sons with disabilities and complex needs, longitudinally across an eight to 10 year span. The focus was on issues in the transition from child to adult services, as the young men reach adulthood. Findings suggest that this transition in characterized by ambivalence and ambiguity, as parents look to evaluate the past, adjust to a different life in the present, and make plans enabling them to envision a hopeful future.

For most families, the transition of a child from adolescence to adulthood results in significant changes in family structure and dynamics. Between the ages of 18 and 25, children typically complete compulsory education programs, leave home, become socially individuated, achieve a measure of personal and financial independence, and transition from child to adult relationships with family members and friends, within culturally accepted parameters (Arnett, 2000). In addition, children begin to attain markers typically associated with adulthood, such as legal autonomy, the right to vote, marriage and parenthood, and full-time employment. This desire for

and experience of individuation is considered normative for children approaching adulthood across a wide range of personal characteristics, including diagnosis of disability. In a UK study of 27 youth ages 14 through early 20s who were diagnosed with learning disability, Tarleton and Ward (2005) reported that these adolescents and young adults had the same expectations of early adulthood, such as leaving home, attending college and living independently, as their non-disabled peers. While many parents of children with disabilities have concern about availability of resources needed for their children to make successful transitions, they desire to support their children toward greater independence and autonomy, with the goal of meaningful participation in preferred activities and vocational opportunities in adulthood (Jivanjee, Kruzich, & Gordon, 2009).

Research on the experiences of families whose children are transitioning from child to adult services indicates that children with disabilities are more likely to live in their parental homes and less likely to attend a post-secondary educational institution or hold a job that pays above the minimum wage than their peers (Davies & Beamish, 2009; Leiter & Waugh, 2009; Murray, 2007; Winn & Hay, 2009). For example, in a survey study of 218 parents of children who were transitioning to adult services in Australia, Davies and Beamish (2009) reported that since leaving school 70% of children were still residing in the parental home, and only 25% had paid employment in community situated jobs, with the majority working twenty or fewer hours per week. Fewer than 25% were enrolled in post-secondary training programs, and only 7% were in university programs leading to a degree or diploma. Approximately half the parents indicated that the post-school transition period entailed "considerable family adjustment" (p. 253). These figures are congruent with data from the United Stated presented by Leiter and Waugh (2009) that "…62% of adults with cognitive but not developmental disabilities, and 73% of adults with both cognitive and developmental disabilities…" resided with family members (p. 530).

While self-determination, empowerment and personal rights have become central components of transition program planning in schools, issues of family responsibility and adjustment through the transition process have been somewhat overlooked (Ankeny, Wilkins, & Spain, 2009; Hingley-Jones, 2009; Tarleton & Ward, 2005). In addition, research suggests that the transition to adulthood may be experienced quite differently in families in which a child has a significant or complex disability that requires high levels of support (Ankeny et al., 2009; Beresford, 2004; Kim & Turnbull, 2004; Knapp, Perkins, Beecham, Dhanasiri, & Rustin, 2007; Murray, 2007). The majority of existent studies of family transition are situated around a single data gathering point, allowing a snap-shot of a family at a point in time. What have been missing are longitudinal studies that examine family functioning across a number of data collection points of the transition process (Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005). Therefore, the

purpose of this study is to explore the perspectives of five mothers of sons with complex needs who were interviewed three times across an eight to ten year period as their sons were transitioning, or had transitioned, from child to adult services. Findings suggest that this transition period is characterized by ambivalence and ambiguity as parents look back to evaluate the past, adjust to a different life in the present, and make plans that enable them to envision a hopeful future.

Transition and Families of Children with Disabilities

Otis (2004, as cited in Murray, 2007) suggested that the school years provide a sense of normalcy for families of children with disability, as children are typically involved in formal education, which situates them with their peers and involves systematic instruction in a setting that is associated with typical development. However, the end of formal education often results in less contact with peers and fewer opportunities for meaningful activity for persons with disability (Beresford, 2004; Murray, 2007; Wynn, Stewart, Law, Burke-Gaffney, & Moning, 2006). While, in many countries, inclusion is both the placement of choice and a child's and family's legal right throughout the school years, adulthood offers fewer certainties (Scorgie & Wilgosh, 2009). Furthermore, while the education of students with disabilities is generally the domain of the educational system, many families report that it becomes largely their responsibility to locate, navigate or even create adult programs that are appropriate to their adult children's needs during the period of and following transition (Beresford, 2004; Davies & Beamish, 2009; Magill-Evans, Wiart, Darrah, & Kratochvil, 2005: Murray, 2007). Research with families during transition has focused, for the most part, on two areas: (1) the experiences of families with the transition process from child to adult services, and (2) the effect of transition on family structure and functioning following end of formal schooling. These will be examined more fully below.

Family Experience with the Transition Process

Though many parents hold positive views of the transition programs offered by the schools their children attend, overall satisfaction with the transition process itself is less favorable (Davies & Beamish, 2009; Murray, 2007; Rueda et al., 2005). While parents maintain that they are best able to make decisions regarding their children's future plans, many report difficulty accessing information regarding available programs and exclusion from equal participation in the planning process (Jivanjee et al., 2009; Rueda et al., 2005; Tarleton & Ward, 2005; Wilgosh & Scorgie, 2006). Because

educational, medical and social service agency professionals are often viewed as the "gatekeepers" to the future training and employment options available for students with disability, parents struggle when they perceive that professionals hold low expectations for their children (Migliore, Grossi, Mank, & Rogan, 2008). In addition, parents may also feel misrepresented where there is a mismatch between their values and goals for their child and those proffered by professionals representing various delivery systems. For example, in a study of 16 Latina mothers of young adults with developmental disabilities, Rueda et al. (2005) found a disconnect between professionals who focused on such things as autonomy, productivity and independence and mothers who valued interdependence, belonging and social connectedness. Rueda et al. concluded that the "… orientation of the mothers and of the delivery system appeared to be at odds" (p. 412), causing mothers to mistrust professionals and view them as adversaries rather than as collaborative team members.

Another difficulty with transition may emerge when the transitioning child's goals are at variance with those proffered by parents and professionals (Magill-Evans et al., 2005). For example, in a study conducted with 41 D/deaf students, both parents and educators focused transition planning on adult involvement in the hearing world, whereas many of the students defined success as transition into the D/deaf community, which Valentine and Skelton (2007) referred to as a "… transition from a family of origin to a family of choice" (p. 115). When an emergent adult has high support needs, parents may feel reluctant to allow the degree of autonomy and independence the adult child desires, due to concerns for personal well-being and safety (Magill-Evans et al., 2005). Furthermore, when the focus of school transition programs is on crafting goals that emphasize child autonomy and self-determination, parents may feel that their own knowledge and concerns about their child are marginalized, limiting meaningful involvement.

During the period of transition, parents also report loss of continuity with and meaningful support from medical and social service personnel, as children migrate from child to adult services (Knapp et al., 2007; Murray, 2007). All too often family members feel as if they are making this transition alone, as the sole purveyors of information regarding their child's past programming. And, because the staff to client ratio is typically higher in adult service venues, parents may find it difficult to craft the same type of close working relationships with professionals that were more typical within the child-centered programs (Beresford, 2004). In addition, parents report having to navigate between a plethora of public and private agencies, programs and services which limits the formation of a unified collaborative team approach (Winn & Hay, 2009).

Parents suggest that when transition programs are ineffective, their children can suffer "missed opportunities for the remainder of their lives"

(Knapp et al., 2007). In addition, some parents suggest that a "gap" exists between the stated transition goals and the actual program outcomes, resulting in expectations that are anticipated, yet not realized (Ankeny et al., 2009, p. 30). Finally, some parents report limited options as their children transition to adulthood, forcing them to choose "the best of a bad lot" (Murray, 2007, p. 27).

The Effect of Transition on Family Structure and Functioning

Research on the effect of transition on family structure and functioning suggests that parents report increased responsibility during and following transition, especially when adult children have conditions that require high levels of support (Beresford, 2004; Davies & Beamish, 2009; Magill-Evans et al., 2005; Murray, 2007). Leiter and Waugh (2009) remarked, "faced with complex and unresponsive service delivery systems, parents face significant challenges when helping their children transition between child and adult systems …" (p. 531) which require considerable time and energy. When adult children reside in the home post-transition, many parents recognize the "… need to provide lifelong support …" to their children (Ankeny et al., 2009, p. 32), which may cause additional strain as parents age (Jivanjee et al., 2009).

Often the demands of caregiving require a parent, typically the mother, to leave the workforce, placing the family under some financial distress at a time when they may be required to assume additional out of pocket expenses relating to the needs of their adult child (Davies & Beamish, 2009; Knapp et al., 2007). Parents who are employed may experience stress when employer expectations are incompatible with their increased caregiving responsibilities (Gottlieb, 2002), or they may choose to forgo promotions or other vocational opportunities if additional work hours or relocation are required (Winn & Hay, 2009). In addition, the fatigue associated with additional caregiving responsibilities may limit time available for involvement in community activities and self care (Davies & Beamish, 2009; Ytterhus, Wendelborg, & Lundeby, 2008).

Rather than accessing existing resources and services, some parents expend significant time and energy to create programs for their emerging adult children. In a study of eight mothers in Australia, Murray (2007) discussed two mothers who created an in-home program rather than sending their daughters to an adult program that served predominantly seniors. Murray reported that the driving force of these mothers was "… to challenge expectations that their daughters fit into existing services, rather than services being personalized to respond to their daughters' individual needs" (p. 28). While this may be a viable recourse for some parents, Magill-Evans et al.

(2005) suggested that when no viable options for acceptable programming appear to exist, parents can begin to feel "trapped" (p. 31).

Transition and Ambiguity

For many parents of children with disability, the period of transition to adult services involves uncertainty. While the period of schooling provided the family with a set routine and consistent responsibilities, the transition from school initiates a different daily schedule, often varied day-to-day, and necessitates the assumption of new responsibilities on the part of parents and caregivers across a number of domains, including vocational, leisure, social-sexual, health and recreation, and legal/financial (Ankeny et al., 2009; Jivanjee et al., 2009). Parents can experience uncertainty about the best course of action in each of these areas, as they balance family, personal and child needs and responsibilities. In addition, parents experience uncertainty about what "adulthood" will signify for their children and themselves. While they observe other families whose children are traversing the typical markers into adulthood, parents whose adult children require high levels of support may experience identities that are out-of-sync with typical stages of family development.

In her work on ambiguous loss, Boss (2004, 2007) indicated that boundary ambiguity occurs when an event causes confusion or stress among members of a family about the division of roles and responsibilities within the family. Studies of parents of children with disability have indicated correlation between parent perceptions of high boundary ambiguity and measures of stress, depression, low self-esteem, pessimism and limited support networks (Carroll, Olson, & Buckmiller, 2007; Mu, Kuo, & Chang, 2005; O'Brien, 2007). High levels of ambiguity across time can cause even "… the most resilient families [to] become vulnerable and immobilized …" (Roper & Jackson, 2007, p. 149). In addition, reflections on stressful life events can trigger ambivalent feelings regarding the event or persons associated with it heightening stress (Boss, 2006). Therefore, helping family members navigate the period of transition from child to adult programs and services is essential to facilitate optimal outcomes (Kim & Turnbull, 2004; Murray, 2007).

The missing stakeholder in much of the literature on transition continues to be the voice of the parent (Beresford, 2004). According to Hingley-Jones (2009) "social policy discourse can oversimplify transition planning" leaving parents feeling marginalized and voiceless (p. 414). She emphasized the importance of spending time with parents and families throughout the transition period, to identify the stresses and strains that may affect family functioning, so that appropriate transition plans can be developed to assure needed supports are in place. The purpose of this study, therefore, was to explore the experiences of five parents who were interviewed across an eight

to ten year time span as their children, all boys, were transitioning, or had transitioned, to adult services to better understand their experiences of the transition process.

Methodology

Data for this study were taken from a larger study of parent life management originally conducted with 15 parents of children with disabilities in Canada. According to Orbuch (1997), narrative interviews enable a researcher to collect "… rich, complex, interwoven reports [in] populations who are facing major life stressors" (p. 461). In addition, narrative accounts allow exploration of ambiguous or dialectical statements regarding an event and the meanings associated with it, and how those may change across time (Carroll et al., 2007; Moule & Streitberger, 1997; Neimeyer, 2002). Phase one of the study consisted of two data collections. First, narrative interviews of approximately one hour in length were conducted, beginning with discussion of the period surrounding diagnosis (e.g., "When did you discover that your child had a disability?") and continuing to the time of interview. As parents iterated their stories, probes focused on three areas: (1) effective life management strategies (e.g., "What strategy was particularly helpful to you at that time?"); (2) parent characteristics (e.g., "What personal characteristics were most important to you as you parented your child at that time?"); and (3) transformational outcomes (e.g., "How have you changed, or what did you learn, as a result of parenting your child?"). Follow-up interviews were conducted either individually or using focus groups approximately six to nine months following the initial interviews. Trustworthiness in the first phase of the study was enhanced through member checks, thick descriptions, an audit trail of coding for theme formation, use of independent data coders, and comparisons of the original interview data with parent written materials (e.g., book chapters about their children).

Phase two of the study occurred approximately eight to ten years following the initial interviews, when parents were contacted regarding willingness to participate in a third interview. Nine participant families were located and six mothers agreed to participate in follow-up interviews of approximately one hour in length, with the first author (Scorgie & Wilgosh, 2008). During the interview parents were invited to provide updated information about the family and then continue the narrative of the family journey, utilizing the same question protocol as the original interviews. Five of the mothers had children who were either in the midst of transition or who had transitioned from child to adult programs. Table 1 contains demographic information for these mothers and their sons at the two phases of the study (all names used are pseudonyms).

During phase one of data collection, four of the five mothers were married and one was divorced. At phase two, two of the married participants were still married (i.e., no change), two had become separated, and the initially divorced participant had recently married. Of the five children represented in the study, all males, two were diagnosed with autism, two with Down syndrome, and one with rare genetic disorder.

Table 1. Parent marital status, occupation and household composition; and child age, diagnosis, living arrangement and school/occupation at data collection.

Phase One (2 data collections)	**Phase Two**
Diane: married, stay at home mother; 4 children; household = 6 individuals **Chad**: 15 [Down syndrome]; fully inclusive schooling in high school	**Diane**: separated, working full time; household = Diane and Chad **Chad**: 25; had been working part-time, but not since serious illness/hospitalization
Maggie: married, working part-time; 2 children; household = 4 individuals **Noah**: 9 [autism]; inclusive third grade classroom with some special services	**Maggie**: separated, working full-time; household = Maggie and Noah **Noah**: 17; eleventh grade special education classroom; remain in same school until age 19
Jennifer: married, stay at home mother; 2 children; household = 4 individuals **Ryan**: 8 [autism]; inclusive third grade classroom	**Jennifer:** married, stay at home mother; household = Jennifer, husband, and Ryan **Ryan**: 18; high school special education transition program
Karen: married, stay at home mother; 6 children (3 adults); household = 5 individuals **Neal**: 11 [Down syndrome]; inclusive fifth grade classroom	**Karen**: married, volunteer; household = Karen, husband, Neal and 2 siblings **Neal:** 19; post high school; working part-time, Special Olympics involvement
Jeri: divorced, working full time; 2 adult children; lived alone **Tim**: 25 [rare degenerative syndrome]; Living in apartment with roommate assistant	**Jeri**: married, working full-time; household = Jeri and husband **Tim**: 33; had been working part-time, but not since spinal cord injury; same living arrangement

The age range of the children during the original interview period was 8 – 24 years (mean age of just over 13 years) and at the third interview was 17 – 33 years (mean age of just over 22 years). Across all three data gatherings child residence was constant, with four children residing in the parental home throughout, and one sharing an apartment with a non-disabled peer who provided support.

All parent interviews were audio recorded and transcribed for data analysis. Notes were taken during the focus group interviews and transcribed. Each participant received copies of both the original (phase one) and the longitudinal (phase two) interview transcriptions for verification of content and member checks. Data were analyzed qualitatively using open and axial coding (Lincoln & Guba, 1985). For the present study the topic of transition from child to adult services was utilized as a sensitizing concept to guide data

analysis and serve as a scaffold for organizing data into themes and sub-themes (Bowen, 2006; Charmaz, 2003; Gilgun, 2002). Both the original and the longitudinal follow-up studies complied with and received university ethical approval.

Findings

Developmental psychologists suggest that life turning points or transition markers offer opportunity for reflection on the past as well as envisioning of the future. As the mothers in this study described their parenting journey through the period of transition from childhood to emerging adulthood, their reflections encompassed three distinct periods: looking back to assess childhood and adolescence (i.e., reappraising the past); describing their daily lives during transition (i.e., managing life in the present); and visualizing future possibilities for both themselves and their children (i.e., envisioning the future). All three phases involved expressions of ambiguity and ambivalence; of valuing and hope.

Reappraising the Past

As parents reflected on their child's adolescent years, especially at the outset of the third interview, four themes emerged: school, friends, family reconfigurations and developmental concerns associated with emerging adulthood. Four of the five emergent adults spent most of their early school years in inclusive settings, typically achieved through the ongoing advocacy of their parents. In fact, three of the five mothers spoke strongly of the need to be an advocate for their sons during phase one interviews (e.g., "We fought … we had to go [all the way] to the provincial minister of education"). However, as they transitioned from elementary school into middle and high school, only one child, Chad, remained in an inclusive classroom. Several of the mothers opined that when their sons were placed in special education classrooms, learning goals shifted significantly. Jennifer spoke of decreasing focus on academic skills as Ryan transitioned to a fully self-contained special education classroom in high school. "In his last high school years, he really didn't progress much at all. More like a day program. He learned some skills, but not as much as I expected. It was a little bit of a disappointment." She felt that many of the expectations that she and other parents were guaranteed at enrollment were never realized. "Everything they promised to do never got carried out …". In the end Jennifer expressed regret that she had not been more persistent about securing optimal programming for Ryan. "I think I probably wasn't assertive enough to go in there and say, 'Look, this is what I want for my son,' and now talking to the other parents, they're disappointed [too]."

Karen described a similar trajectory for Neal from full inclusion in elementary school to a largely segregated high school experience.

The school experience was very successful up until the end of grade nine. When he entered high school there was less inclusion, and so we were a little disappointed in that … He was integrated for two classes and then spent the rest of the day in a segregated setting doing simple math, journaling – those kinds of things.

Though Maggie, whose son was still in school during the final interview, also spoke of limited integration following elementary school, she expressed overall satisfaction with the ethos of the school, a private religious-based institution, and Noah's sense of belonging during his time there.

Chad was the only student who continued throughout high school in inclusive classroom settings, though Diane admitted it was far from ideal. "I really felt that there was lots of resentment … . I think we might have had one or two teachers that were sort of on board, but not really committed." Chad's attendance at high school ended rather abruptly after an altercation with a teacher resulted in Diane withdrawing him from school and crafting a transition program for him in other settings. Though the new program was one which fostered acceptance and belonging, the disappointment for Diane was that Chad was unable to receive his certificate marking completion of school.

Even though the school he was at tried to have him included in the graduating class, to have the picture and go to the ceremony and stuff, this [high] school wouldn't have any part of it. So it was really unfortunate … and [he] was left very much without any closure.

The reflections on end of schooling were especially difficult for several of the mothers because there was no opportunity to redeem a negative experience. For example, Jeri, whose son, Tim was in a segregated setting throughout his entire schooling, expressed sadness for all the typical experiences of adolescence that he missed out on that were now unrecoverable (e.g., "it's all lost …"). However, as the school experience became more segregated several of the mothers, including Jeri, crafted inclusive experiences outside of the school day through involvement of their sons in community activities, including scouting, sports, work and volunteer programs. Nonetheless, there were clearly ambivalent feelings regarding reflections on the school years, often mixed with expressions of regret which, for some, triggered a measure of self-blame.

As they reflected on the transition period, mothers also discussed the social disconnect between their sons and former peer friends, often due to differences in interests and engagement ability. Karen opined, "… the friendship element in the lives of handicapped children, I think, is one of the most challenging – the lack of friends." Maggie stated that because Noah's cognitive ability was significantly below that of his peers, her goal has always been "… to help other people in [his] world understand [him],"

though she suggested it became increasingly inappropriate for her to serve as liaison between Noah and his peers as he entered adolescence.

The three mothers who experienced separation or divorce also articulated feelings of ambiguity regarding their child's father. Diane spoke of her husband's inability to accept life-long caregiving responsibilities as one of the reasons for their separation which occurred during the transition period. She discussed Chad's confusion over the absence of his father. "It's not that he doesn't have contact … . But there's hurt. There's father-grief there." Jeri reflected on the need to keep her ambivalent feelings toward Tim's father, who left the marriage when Tim was young, in check, instead sharing Tim's pleasure during the intermittent times in which his father engaged in his life. "I had to go through a little bit of adjustment in terms of my attitude about a few things; but it was really to be focused on Tim and his needs." Maggie, in turn, discussed the importance of maintaining a supportive relationship with Noah's grandparents despite separation from Noah's father, which also occurred during the transition period.

Finally, as their sons approached adulthood, several mothers discussed challenging or inappropriate social behaviors, mostly focusing on relationships with girls and women. Karen mentioned an incident on the school bus in which a group of boys persuaded Neal to make inappropriate comments to a young girl. Jennifer also shared difficulties with Ryan's growing interest in relationships, focusing on how he would inappropriately approach and talk with strangers. "He has no idea what it's all about, but he'll [say] 'Oh, you're pregnant. Oh, that's my son.' And he will actually tell that person that it is his baby." She also mentioned having to terminate the employ of a young adult female in-home worker due to Ryan's inappropriate behaviors.

Reflections on the past were characterized by ambivalence for a number of reasons. First of all, when a phase of life is past (such as when a child graduates from high school), a parent cannot go back and change the outcome. Retrospective reflections allow opportunity for drawing inferences that perhaps the demands of living in-the-moment do not. And while parents may be aware of the academic limitations of their children, their strong belief in the importance of social inclusion with peers may seem out-of-sync with the programs offered and the value-system found within high schools. Finally, many parents become fatigued with the ongoing need for and demands of advocacy. Thus, as they are in the process of transition, parents may struggle with ambivalent memories of the past.

Managing Life in the Present

As the mothers described life in the present, four major themes emerged: the amount of down time and its affect on their sons since leaving formal schooling; parent responsibilities to secure appropriate adult programs and supports; family and health difficulties during the transition period; and

securing a meaningful adult life for their child following transition. Three mothers spoke of long periods of down-time for their sons following the end of formal schooling, due, in part, to fewer hours of funded support for personnel. Karen remarked, "I'm finding it difficult to keep him busy all the time when he's not with his worker [who was only available 14 hours a week] … . I see him looking bored a lot of the time now." Long periods of inactivity seemed to aggravate repetitive and self-stimulatory behaviors and increase frustration and anxiety in three of the emerging adults, necessitating need for program modification. Karen commented, "We have to go to the government again to renegotiate the contract to increase the time [Neal] has with his worker."

Dissatisfied with conventional adult programs in largely segregated settings, three of the mothers chose to develop their own programs for their sons, which involved considerable time and energy (e.g., scheduling, provision of private transportation), and securing and retaining appropriate support personnel for various activities. Diane remarked, "We just kind of created our own world for Chad." She described a number of different activities he was engaged in throughout the week; such as working at a video store, recycling at an office building, cooking at home, banking, shopping, and volunteering in several venues. "For him, he just feels good about himself, and so he should." Diane discussed the ongoing need to reintroduce and sometimes modify Chad's work experiences when local businesses changed management and new personnel were not as receptive to Chad's involvement. On the other hand, Jennifer described a difficult decision to enroll Ryan in a local day program for adults with disabilities, though she had some misgivings about its suitability. "So I just thought that it would be so much more work for myself; trying to figure out, you know, [how] to fill the day … so we'll try it out and see how it goes." Maggie spoke of the need to begin the search for a suitable day program for Noah that would fit into her own employment schedule.

Each of the mothers described at least one difficulty within the immediate family that had caused significant stress between phases one and two of the study. Both Chad and Tim experienced serious health concerns that involved extensive hospitalization and surgery. One of Karen's daughters, still residing in the home, and Maggie's husband were diagnosed with mental health disorders. Diane had sustained injuries from an accident from which she was still recovering (e.g., "I don't have a lot of extra right now"); and Ryan had been experiencing side effects of medications that were causing volatile and aggressive outbursts. Several mothers spoke of aging family members needing assistance or loss of family members who had previously been part of their support networks. Karen observed, "There are times that I've felt, in the past little while, very overburdened – two special needs children and then an elderly mother who is becoming quite disabled, and a husband who's away a lot … . Right now I really don't have anyone to turn to [for] help." In addition,

the ongoing caregiving needs of their emerging adult children caused many to feel out-of-sync with their peers. Jennifer concluded, "Sometimes I get bitter. You know, there's deep hurts, I think. It's hard to deal with especially when you see your friends' kids at the same age, who are going to university, or are getting engaged, or you know, they have the empty nest already, and they have the freedom to come and go as they please, and we don't".

Despite the difficulties these parents faced as their children transitioned from formal schooling, each stated that their fundamental desire was to craft a life in the present that was meaningful for their emerging adult children. Many spoke of allowing their child's interests to shape programming. Jeri shared how she helped Tim combine his sociable temperament and love of music through hosting Friday night jam sessions at his apartment (e.g., "They were having pot lucks … and they all had tee-shirts and jammed away. They just had a wonderful time"). Karen reported that Neal, who loved sports, currently worked at a college fitness center in return for membership in the facility, where he was able to maintain an exercise routine to facilitate valued participation in the Special Olympics. By focusing on meaningful activities, parents felt they were giving their adult children a rich and enjoyable life in the present. In addition, several iterated that during the transition period they had emerged to a new level of acceptance of their child's diagnosis. As Maggie stated, "I think that I'm totally more accepting than I was … I think that I hoped that one day he would be able to – and now I realize that that's not going to happen. … I think I am more at peace with it now."

Envisioning the Future

As the five mothers envisioned the future for their children and their families, two themes emerged: uncertainty across a number of domains, and the need for comprehensive long term planning. Parents mentioned a number of unknowns as they faced the future. Tim's recent hospitalization, combined with his genetic condition, had caused Jeri to wonder about his long term prognosis. She stressed that since his release from hospital, "every day is important." Jeri, Karen and Diane spoke of their concern about government cuts to funding for adult programs, service personnel and even health care for persons with disability, something they felt was already occurring.

Each parent also spoke of the need to focus on comprehensive long term planning for her adult son. Housing was a prevailing topic. Jennifer indicated the need to begin search for an out-of-home adult living arrangement for Ryan. "He's getting more difficult and I think it would benefit him more to be with his peers." Maggie and Diane indicated that, given how secure their sons felt about living in the family home and the support they received from the immediate community, perhaps they would be the ones to eventually move away. As Diane shared, "[Chad] is very clear that this is where he needs to stay … . The rest of us can move out if we want." Jeri, Karen,

Maggie and Jennifer spoke of the eventual need of their son's siblings, as well as extended family members, to provide significant support. Concerning Noah's sister, and only sibling, Maggie stated, "I think we both avoid looking at what reality will look like. She knows that she will be responsible for him." Maggie's goal in the meantime was to assemble a number of overlapping support networks involving extended family members. Jeri mentioned that Tim's adult brother was very active in his life and purposively chose a spouse who would be committed to supportive care for Tim. Several of the mothers commented that, due to the multitude of uncertainties and the stress associated with such ambiguity, they chose, instead, to focus on the present. According to Diane, "The future is very uncertain for us now … . So at the moment, we're just trying to be in the moment. And, if that's denial, then that's where I'm at."

At the end of the phase two follow-up interviews parents were asked to reflect again on how they had changed through parenting their sons. Mothers shared that their child had given them appreciation for human interdependence, taught them what is important in life, and modeled how to let go of the insignificant, to relax and to enjoy the here and now. Jeri remarked, "It has instilled in me a value system that is very solid … respect for humanity … that all people have value and contribute something. I've dismissed the idea that if you have a disability you're a burden." Several of the mothers spoke of the importance of advocacy. Maggie asserted, "Advocacy is my passion … I think I've learned how to speak for myself as well as how to speak for other people who cannot speak for themselves," a skill that has also made her more effective in her vocational employment as a nurse. Throughout both interviews each mother underscored the positive characteristics of their sons and of their family journeys. Diane concurred, "I think all too often we're given the perception that life and opportunities are limited for our kids. And they are not … . But with the lows come the highs, and those highs are incredible experiences. You will go down a path you never imagined [but] that path can be as wonderful as you are able to make it."

Discussion

Times of transition, such when a child moves from adolescence to adulthood, offer opportunities to assess the past and envision the future, all the while adjusting to the present. For most families the transition of children to adulthood involves a new family structure as parents typically have less responsibility for the physical, social and vocational needs of their children. However, when a child has a disability requiring high levels of support, family responsibilities may increase as the emerging adult transitions from child to adult services. According to Murray (2007), emerging adulthood is less a period of transition, but rather constitutes a continuation of caregiving

which "… present[s] new challenges and obstacles" to the family (p. 29). This reality suggests a number of considerations.

First, transition may trigger a significant readjustment of family roles and responsibilities as the family assumes often greater responsibility for meeting the needs of the person with disability. As parents reassess the past there may be regret for lost opportunities as well as disappointment that educational goals and objectives were not attained. Hingley-Jones (2009) discussed the ambiguity that can result when parents fluctuate between internal (e.g., "I could have done more") and external (e.g. "the system let my child down") accountability for outcomes judged as less than ideal. She indicated that at times externalizing blame might be an effective strategy for warding off depression. In addition, as they navigate the transition period, parents may find that strategies that worked in the past, such as a focus on personal advocacy for inclusive environments, may not be as effective as their children move into adulthood, with differing systems and regulations in place. In fact, it may be that those parents who were strongest advocates for inclusion of their children while in school, may struggle most with the lack of inclusiveness as their children move through adolescence into adulthood (Scorgie & Wilgosh, 2009). This might suggest that a focus on individual, parent-oriented skills, such as advocacy, might be balanced with greater emphasis on the responsibility of the school and community to support inclusion of persons with disability and their families throughout the developmental cycle (Ytterhus et al., 2008).

Secondly, initiating transition programming earlier in a child's schooling with both vocational and family needs and goals in mind may foster smoother transitions (Carter et al., 2010; Roberts, 2010). Carter et al. (2010) found that students with disability who had supported employment opportunities while in high school were more likely to have paid employment once they graduated. In addition, transition programming should consider both the needs of the person with disability and those of family members who retain responsibility for care. Kim and Turnbull (2004) suggested Person-Family Interdependent Planning as a transition model which safeguards quality of life for all members of the family, and situates planning within a network of collaborative, cross-agency supports. Similarly, Wynn et al. (2006) described implementation of a community capacity-building program focused on identifying assets within the local community that can serve as resources for families and persons with disabilities, and scaffolding contacts between potential employers and service organizations in the community and family members during the transition period.

Thirdly, defining adulthood may be difficult when a child has a disability requiring high levels of supports. Certainly the typical markers associated with attaining adulthood may be absent (Beresford, 2004). In addition, the enhanced realization of the need to provide ongoing, lifelong caregiving may come at a time when parents are facing life changes of their own, resulting in caregiver fatigue. Jivanjee et al. (2009) suggested that viewing transition as modified or

graduated independence, can allow both an appropriate level of individuation and self-determination for the emerging adult, as well as permit parents to define boundaries that enable them to secure needed autonomy, respite and renewal. Transition programs may also include greater focus on long-term planning which engage a wider range of family members, including siblings. In fact, it might be argued that siblings have their own transition planning programs geared to the types of responsibilities, such as guardianship or financial decision-making, that they may be required to undertake in the future.

Finally, the period of adjustment during transition might suggest that family life management is cyclical in nature, rather than linear (Wilgosh & Scorgie, 2006). According to Boss (2006), "the challenge of constructing and reconstructing one's identity, not according to linear stages but rather within a shifting context of family and society, indeed reflects the real-life experiences of many people today" (p. 118). Viewing transition using a systems approach might help offset the typical consensus that blame for lack of adjustment resides primarily within the family. Boss (2006) suggested that feelings of ambiguity are more often triggered by external situations than they are by intra-family issues. Because parents of children with disability have little control over the external variables affecting the welfare of their emerging adult children, such as funding for health care and vocational training, friendship formations, or acceptance of persons with disability in society and the workplace, they may find it difficult to resolve their own feelings of ambivalence, which contribute to ongoing anxiety.

These parents' experiences and reflections provide insights into the inadequacies of existing educational and social networks to support the emergent needs of young people with disabilities as they transition with hopefulness into an adulthood where communities and support systems are not necessarily in tune with the individual's and family's hopes and expectations. Parent expressions of ambiguity and frustration may appear to overshadow their greater desire, which is to secure a life that is valued and meaningful for their children as they transition to adulthood.

References

Ankeny, E. M., Wilkins, J., & Spain, J. (2009). Mothers' experiences of transition planning for their children with disabilities. *Teaching Exceptional Children, 41*(6), 28-36.

Arnett, J. J. (2000). Emergent adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469-480.

Beresford, F. (2004). On the road to nowhere?: Young disabled people and transition. *Child: Care, Health and Development 30*(6), 581-587.

Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage and Family, 66*, 551-556.

Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss*. New York: W.W. Norton.

Boss, P. (2007). Ambiguous loss theory: Challenges for scholars and practitioners. *Family Relations, 56*(2), 105-111.

Bowen, G. A. (2006). Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods, 5*(3), 1-9.

Carroll, J. S., Olson, C. D., & Buckmiller, N. (2007). Family boundary ambiguity: A 30-year review of theory, research, and measurement. *Family Relations 56*(2), 210-230.

Carter, E. W., Ditchman, N., Sun, Y., Trainor, A. A., Swedeen, B., & Owens, L. (2010). Summer employment and community experiences of transition-age youth with severe disabilities. *Exceptional Children, 76*(2), 194-212.

Charmaz, K. (2003). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies for qualitative inquiry* (2nd ed., pp. 249-291). Thousand Oaks, CA: Sage.

Davies, M. D., & Beamish, W. (2009). Transitions from school for young adults with intellectual disability: Parental perspectives on "life as adjustment". *Journal of Intellectual and Developmental Disability, 34*(3), 248-257.

Gilgun, J. F. (2002). Conjectures and refutations: Government funding and qualitative research. *Qualitative Social Work, 1*(3), 359-375.

Gottleib, R. S. (2002). The tasks of embodied love: Moral problems in caring for children with disabilities. *Hypatia, 17*(3), 225-236.

Hingley-Jones, H. (2009). Developing practice-near social work research to explore the emotional worlds of severely learning disabled adolescents in "transition" and their families. *Journal of Social Work Practice, 23*(4), 413-428.

Jivanjee, P., Kruzich, J. M., & Gordon, L., J. (2009). The age of uncertainty: Parent perspectives on the transitions of young people with mental health difficulties to adulthood. *Journal of Child and Family Studies, 18*(4), 435-446.

Kim, K. H., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons with Severe Disabilities, 29*(1), 53-57.

Knapp, M., Perkins, M., Beecham, J., Dhanasiri, S., & Rustin, C. (2007). Transition pathways for young people with complex disabilities: Exploring the economic consequences. *Child: Care, Health and Development, 34*(4), 512-520.

Leiter, V., & Waugh, A. (2009). Moving out: Residential independence among young adults with disabilities and the role of families. *Marriage and Family Review, 45*, 519-537.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Beverly Hills. CA: Sage.

Magill-Evans, J., Wiart, L., Darrah,J., & Kratochvil, M. (2005). Beginning the transition to adulthood: The experiences of six families with youths with cerebral palsy. *Physical and Occupational Therapy in Pediatrics, 25*(3), 19-36.

Migliore, A., Grossi, T., Mank, D., & Rogan, P. (2008). Why do adults with intellectual disabilities work in sheltered workshops? *Journal of Vocational Rehabilitation, 28*(1), 29-40.

Moule, N.J., & Streitberger, S. (1997). Stories of suffering, stories of strength: Narrative influences in family nursing. *Journal of Family Nursing, 3*, 365-377.

Mu, P., Kuo, H., & Chang, K. (2005). Boundary ambiguity, coping patterns, and depression in mothers caring for children with epilepsy in Taiwan. *International Journal of Nursing Studies, 42*, 273-282.

Murray, S. (2007). Families' care work during the transition from school to post-school for children with severe disabilities. *Family Matters, 76*, 24-29.

Neimeyer, R. A. (2002). Traumatic loss and the reconstruction of meaning. *Journal of Palliative Medicine, 5*(6), 935-942.

O'Brien, M. (2007). Ambiguous loss in families of children with autism spectrum disorder. *Family Relations, 56*(2), 135-146.

Orbuch, T. L. (1997). People's accounts count: The sociology of accounts. *Annual Review of Sociology,23*, 455-478.

Roberts, K. (2010). Topic areas to consider when planning transition from high school to postsecondary education for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disorders, 25*(3), 158-162.

Roper, S. O., & Jackson, J. B. (2007). The ambiguities of out-of-home care: Children with severe or profound disabilities. *Family Relations, 56*(2), 147-161.

Rueda, R., Monzo, L., Shapiro, J., Gomez, J., & Blacher, J. (2005). Cultural models of transition: Latina mothers of young adults with developmental disabilities. *Exceptional Children, 71*(4), 401-414.

Scorgie, K., & Wilgosh, L. (2008). Reflections on an uncommon journey: A follow-up study of life management of six mothers of children with diverse disabilities. *International Journal of Special Education, 23*(1), 103-114.

Scorgie, K., & Wilgosh. L. (2009). Including as a *care-ful* journey: A parent's perspective. *Developmental Disabilities Bulletin, 37*(1/2), 203-220.

Tarleton, B., & Ward, L. (2005). Changes and choices: Finding out what information young people with learning disabilities, their parents and supporters need at transition. *British Journal of Learning Disabilities, 33*, 70-76.

Valentine, G., & Skelton, T. (2007). Re-defining "norms": D/deaf young people's transitions to independence. *The Sociological Review, 55*(1), 104-123.

Wilgosh, L., & Scorgie, K. (2006). A theoretical model for conceptualizing cross-cultural applications and intervention strategies for parents of children with disabilities. *Journal of Policy and Practice in Intellectual Disability.* 3(4), 211-218.

Winn, S., & Hay, I. (2009). Transition from school for youths with a disability: Issues and challenges. *Disability and Society, 24*(1), 103-115.

Wynn, K., Stewart, D., Law, M., Burke-Gaffney, J., & Moning, T. (2006). Creating connections: A community capacity-building project with parents and youth with disabilities in transition to adulthood. *Physical and Occupational Therapy in Pediatrics, 26*(4), 89-103.

Ytterhus, B., Wendelborg, C., & Lundeby, H. (2008). Managing turning points and transitions in childhood and parenthood. Insights from families with disabled children in Norway. *Disability and Society, 23*(6), 625-636.